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Texas Alzheimer's News

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and the Texas Council on Alzheimer's Disease and Related Disorders**

Understand and Help Me

By Howard Gruetzner, M.Ed.

Quality Alzheimer's care depends upon our ability to recognize and respond to the needs of persons with dementia. These needs are not as obvious as they seem. Sometimes people with Alzheimer's can help us. They may be aware of needs but are unable to communicate them to us in ways we understand. We need to be aware of other ways they may communicate needs. They might act out as a result of their needs not being recognized. They might withdraw from any external demands. Their behavior offers the opportunity to identify unmet needs that cannot be expressed in any other way.

Behaviors we refer to as problems may be expressions of unmet needs. Such behaviors include anger, agitation, withdrawal, denial, not cooperating, making demands, and insisting on performing tasks that are no longer appropriate. We need to question whether there are other ways to interpret and

understand these behaviors. If we can see these "problems" as communication of needs, we might be able to help people with Alzheimer's in new creative ways. Seeing problems from the individual's perspective creates new opportunities for understanding the person with Alzheimer's disease. It gives us a chance to respond in more meaningful ways.

We need to look for new ways to understand the nature of dementia itself, according to Tom Kitwood, author of *Dementia Reconsidered: the person comes first*. For example, if we could see that the problem was not the person with dementia but the social environment in which the behavior occurs, we might be able to find other ways to understand and help people with challenging behaviors. Rather than trying to change the person with Alzheimer's, we may need to change our perspectives or the environment. Whether intended or not,

behaviors often communicate something about the needs of people. We must look closer to understand the message they carry. In his book, *Hearing the Voice of People with Dementia: Opportunities and Obstacles*, Malcolm Goldsmith cites the story of a professional caregiver who challenged himself to understand why a resident of the facility in which he worked walked around repeating the words "help me", over and over again. Staff responded by asking how they could help her: Was she hungry or thirsty? Did she want to go to the bathroom? Was someone bothering her? She did not respond to their queries, and staff became increasingly frustrated. They stopped responding.

What does the behavior of walking around and pleading, "Help me!" mean? How can we understand this behavior differently?

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One way to approach this challenge is to look at the “ABC’s” of the behavior. “B” stands for the behavior — the woman walking around and saying, “Help me,” to no one in particular. “A”, the antecedent of the behavior, or what happens before the behavior, is not so evident in this example. The woman is not addressing a particular person with her request, though her tone seems to be one of hopelessness or helplessness. “C” stands for consequence — what happens after the behavior. The frequency of her desperate pleading is unaffected by the responses of staff. Some would argue that the staff was reinforcing the behavior by giving attention. Since the affect of the woman does not suggest that she finds their response rewarding, this argument doesn’t fit. Eventually, staff stopped responding to her.

She is seeking something she is not getting. She really has two problems: she has unmet needs; and the culture of care in which she resides cannot help her with those needs. Using the “ABC” approach to behavior can be helpful, yet there are times when this approach obscures the deeper human needs of people with dementia — especially when the needs are internal and cannot be clearly verbalized.

If we are to be open to other ways of understanding the

behavior of people with dementia, we need to be aware of how we tend to interpret behaviors: How do we view different behaviors? Do we take into account other factors that affect what they can do? Do we tend to be judgmental because they are not cooperating? Do we quickly conclude the problem is caused by a need for attention and blame the person for trying to meet their need? Do we appreciate how behavior is affected by the environment and relationships with people? Our beliefs about behavior and what causes it greatly influence our response to those we are helping.

Here are some examples to consider: If a person’s performance is not up to standards, do we perceive a lack of effort? If we know the person is having some difficulty compensating for problems related to symptoms of dementia, are we able to appreciate her behavior and her effort, and help her adapt? Even though it requires more effort? We might interpret angry, hostile behavior in someone as a sign that the person is “mean”, and we feel resistant to helping him. If we viewed the same behavior as a reaction to the overwhelming demands that exceed the person’s capacity to adapt, can we respond to him differently? If the person with Alzheimer’s refuses to stop driving the family car because he has no awareness that his driving



abilities have changed, will we empathize with him — even though we cannot permit him to drive again? Pressed to deal with changes that do not fit into our usual views of behavior we may unwittingly respond to the person with dementia in a manner that is negative and judgmental. We may manage behavior, but fail to address important needs.

People with Alzheimer’s are still people, and they have many of the same needs they have always had. Tom Kitwood has identified important psychological needs of persons with dementia: attachment, comfort, identity, inclusion, and occupation. All of these overlap and connect through the central human need for love. Some behavior problems are responses to these unmet needs; others are reactions to fresh losses in these areas. People with Alzheimer’s have been able to provide for many of their own needs and may be able to continue doing so if we are alert to clues. If we know what they want and need, we can assist them in finding other

ways to meet their needs when those they have depended on are no longer available to them.

Memory loss is a good example. It creates many needs. Memory — together with cognitive abilities — enables us to solve problems, provide for our needs, and adapt to changing situations. Security is a very powerful need heightened by the changes in these abilities because memory helps us maintain a sense of order and predictability. When people with Alzheimer's shadow caregivers we are seeing a good example of the person with Alzheimer's trying to meet his own need, or communicate the need for comfort, security and attachment to his caregiver. Being separate enhances one's insecurity and one's need to be connected to another supportive person. Asking something over and over again can be seen as an effort to keep in touch with one's world in other ways.

Our beliefs about behavior are linked to our understanding of what we see and the appropriateness of our response to the needs of persons with dementia. We have considered important needs of persons with dementia, and looked at a few examples of a person's attempts to communicate needs that might otherwise be viewed as a problem. In conclusion, it is appropriate to finish the story of the woman who walked about repeating the words, "Help me."

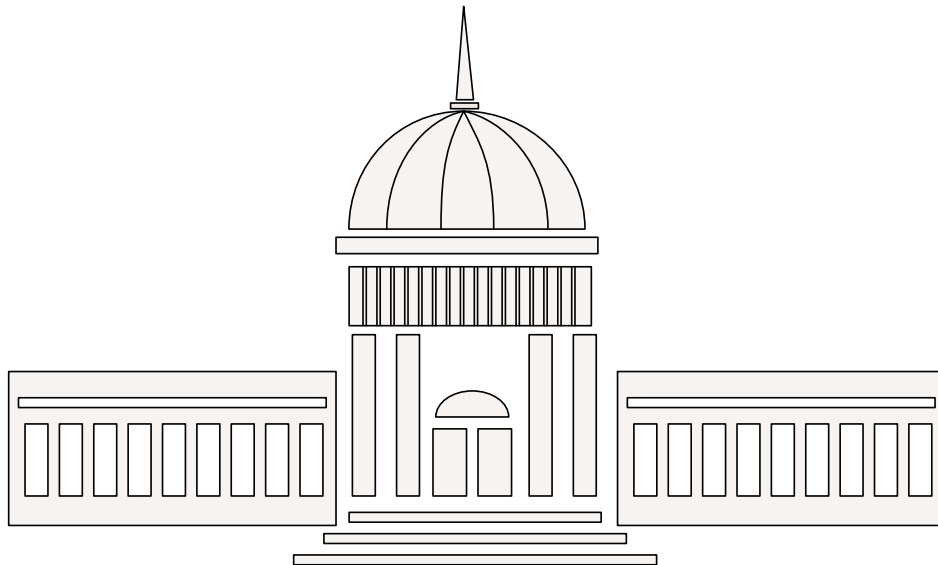


Further exploration of the words led the staff to realize that it had a meaning much deeper than her transient needs of the moment: she meant, "Help me find myself again." Staff then bypassed her question, responding instead with personal attention like waves or smiles whenever she said, "Help me." Their new response reduced the frequency of her behavior, and when she did say, "Help me," the woman began to follow up with a specific request.

People with dementia communicate their needs with behaviors we might label as problems. People with dementia may know more about their needs than they are able to say

in words, and we are not able to understand until we look deeper for what the behavior means.

Howard Gruetzner is Director of Elder Services for Heart of Texas Region Mental Health and Mental Retardation and author of Alzheimer's: A Caregiver's Guide and Sourcebook, now in its 10th printing. The 4th Revision will be available in May 2001.



Legislative Update

Alzheimer's Advocates to Meet in February

The Alzheimer's Association Coalition of Texas will host an Advocacy Day at the Capitol in Austin on Tuesday, February 20, 2001. Family members, caregivers and friends of those with Alzheimer's, and other advocates will meet at the Sheraton Hotel to discuss issues concerning Alzheimer's disease and the impact current legislation could have on those living with the disease. The Coalition platform for the 2001 Legislative Session will be presented with critical talking points outlined. A chartered bus will deliver advocates to the Capitol after lunch for visits with legislators.

Advocates from across the state, representing the fourteen chapters of the Alzheimer's Association, have been working on platform issues since early summer. In a legislative year that many believe will be difficult at best, the Coalition's chief goal is to make sure legislators don't forget about the issues that are becoming increasingly important to families

struggling with Alzheimer's disease. These issues are being developed into a platform statement and will be included in a "leave behind" packet for every legislator. The packet will also include basic information about the disease and the services provided by Alzheimer's Association chapters across the state.

The Coalition platform will concentrate on three key issues for the upcoming session. These include:

1. The Community Alzheimer's Resource and Education (CARE) Program:
 - a. To maintain funding at least at current levels.
 - b. To expand the program with the goal of having at least one CARE site in every Texas Department of Human Services (TDHS) region in the state.
 - c. To incorporate a pilot for dementia-specific adult day care.
 - d. To increase funding for respite care.
2. Texas Index for Level of Effort

(TILE): To ask TDHS to review and revise TILE to better account for the varying resource needs of nursing home residents with Alzheimer's disease. (This was also a consensus recommendation of the Senate Committee on Human Services on long-term care).

3. Community Based Alternatives Program: To demonstrate support for increased funding.

The Coalition continues to monitor pending legislation that may impact the lives of Alzheimer's patients and families and will help support other initiatives that will enhance the quality of life for these families. The Alzheimer's Association is also monitoring Federal legislation that may affect Texas families and will report on any new developments during Advocate's Day.

For more information on the Alzheimer's Association Coalition of Texas Advocate's Day at the Capitol, call Judy Miller at 512-454-5476, or contact the Alzheimer's Association chapter nearest you.

Best Practices

Successful Activity Planning

*By Kim Nemec, M.A., L.P.C.
Program Director, Barton House*

Planning activities takes on a new role when working with a person who has Alzheimer's disease. The following are important concepts that need to be remembered when working with people who have Alzheimer's.

The art of activities is not in what is done: it is in the doing. The process of the activity is always more important than the result or end product. If an activity such as folding towels is accompanied by smiles, conversation, friendly gossip, discussion and praise for a job well

done, it does not matter if the towels are not folded with perfect edges.

Activities should be individualized and tap into past interests and skills.

The person's life history should be mined for ideas about activities. A person who enjoyed playing cards, for example, might not be able to play poker or bridge anymore, but might enjoy playing a game with assistance, shuffling the deck, talking about cards or simply watching others play.

Activities should be adult in nature.

Activities that are unnecessarily juvenile can provoke frustration, even anger. There is a difference between "childlike" and "childish."

Activities could recall a person's work-related past.

Work played an enormous role in the lives of people with

Alzheimer's. A farmer may still enjoy planting seeds. A home-maker may like to discuss canning fruits.

Activities should stimulate the senses (sight, smell, hearing, taste, and touch).

It is important to stimulate more than one sense. For example, gardening involves touching wet soil, smelling different flowers, hearing the sound of footsteps on autumn leaves, tasting fruit off a tree, and seeing vivid colors in a variety of plants.

Doing nothing can actually be doing something.

Even good friends enjoy quiet times together, perhaps just sitting in the living room listening to music or watching the world go by through a window.

Activities should tap into remaining physical skills.

Activities should take advantage of the person's physical condition by exercising, walking, doing chores, or other physical tasks.

Sometimes activities must be initiated by others.

People with Alzheimer's disease lose the ability to initiate activities. Even the best-planned activity will fail if the person cannot get started.

Activities should be voluntary.

Most people with dementia will not do something they do not enjoy or find satisfying. No one should be forced to do something. If an activity is started in front of the person, he or she may become interested and then take over the task.



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about old times, smell a new scented soap, or tell a joke.

Activities can be short.

The person's attention span at times makes it difficult for him or her to be involved in an extended activity. Even very brief activities, repeated often, can fill a day. For example, reading a number of short poems

throughout the day or sweeping the kitchen floor often.

Activities are everywhere.

Almost everything can become an extended, interesting activity. A simple handshake can lead to a discussion about fingernail polish,

gloves, work done by hand, "lifelines," rings on fingers, engagement rings, weddings, and more.

It is important to focus on the process of activities rather than the product. The secret is not necessarily in what you do-it's in the doing.

Adapted from Bell and Troxel, The Best Friends Approach to Alzheimer's Care (1997).

*Tell me and I'll forget.
Show me, and I may
not remember.
Involve me, and I'll
understand.*

*~ Native American
Proverb*

Activities of daily living:

Caregivers should recognize that some of the most difficult personal care chores can become more positive when creatively applied. Caregivers can take a few extra moments while helping a person bathe or dress to talk

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Viewpoints expressed in this newsletter do not necessarily reflect those of the Texas Council on Alzheimer's Disease and Related Disorders or the Alzheimer's Association Coalition of Texas.

Answers to JUMBLE:

BEHAVIOR
ACTIVITY
LEGISLATIVE
CONSORTIUM
DIAGNOSIS
SUPPORT

VALIDATION THERAPY



Designed for activity professionals working in adult day care, assisted living and long term care facilities. Includes programming ideas, resources, and information on all aspects of activity planning.

ElderCare Online is designed for people caring for aged loved ones. Contents include homecare and independent living; insurance coverage; legal and financial matters; longevity and wellness; residential options; transitions and spirituality; and a section dedicated to Alzheimer's disease and dementia. The Alzheimer's section includes medical aspects, stages of Alzheimer's, behavior management techniques, activities planning, family issues in caregiving, and tips and techniques for performing personal caregiving tasks.

R E H A V I O B

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C A V Y T I I T

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V E G I S L A T I L E

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T O R S U I M C O N

N A G I D O S I S

○ ○ ○

P R U S T O P

○ ○

Now arrange the circled letters to form the answer to this clue:
It's what Naomi Feil does best.

Answers on page 6

The Coalition represents the 14 chapters of the Alzheimer's Association in Texas, and their regional offices. The Alzheimer's Association is a national voluntary health organization founded in 1980 to provide information and services, including a telephone help line, family support groups, educational programs, a lending library, the Safe Return program for wanderers, in-service training, and multicultural outreach programs. The mission of the Coalition is to advocate for the improved quality of life for Texans affected by Alzheimer's disease and related disorders.



The Council was created by legislative mandate in 1988 to serve as the state's advocate for persons with Alzheimer's disease and those who care for them. Members are appointed by the Governor, the Lieutenant Governor, and the Speaker of the House to coordinate statewide research and education efforts, and to disseminate information on services and related activities available for persons with Alzheimer's disease to the medical and academic communities, family and professional caregivers, and the public.

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